DOCUMENT RESUME

ED 276 197 EC 190 963

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TITLE Past and Present Implications for Rehabilitation. Section I.
PUB DATE May 86
NOTE 10p.; In: Walker, Sylvia, Ed. And Others. Equal to the Challenge: Perspectives, Problems, and Strategies in the Rehabilitation of the Nonwhite Disabled. Proceedings of the National Conference of the Howard University Model to Improve Rehabilitation Services to Minority Populations with Handicapping Conditions (1984); see EC 190 962.
PUB TYPE Speeches/Conference Papers (150) -- Viewpoints (120) -- Reports - Descriptive (141)

EDRS PRICE MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS Advocacy; *Blacks; *Disabilities; *Federal Aid; *Federal Programs; History; Incidence; *Minority Groups; Negative Attitudes; *Rehabilitation Programs; *Research and Development Centers; Staff Role; State Aid

ABSTRACT

This document contains two papers about past and present implications for rehabilitation given at a national conference on the needs of the nonwhite disabled population. In the paper "Rehabilitation for the Nonwhite Disabled: A Formidable Challenge," E. Anderson states that blacks are overrepresented among the handicapped in America. Through discussion of the impact of federal cutbacks on handicapped minorities and of negative attitudes toward the handicapped, Anderson calls for intense advocacy by those who work with, support, and represent the minority handicapped. In the paper "Redefining the Unacceptable," D. Fenderson presents a historical overview of the emerging role of rehabilitation and related services and how they have evolved to reflect conventional approaches. The formation of the National Institute of Handicapped Research, and its funding options designed to support grants to improve services to special populations, are highlighted. (CB)

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1 • Rehabilitation for the Nonwhite Disabled: A Formidable Challenge

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Abstract

This article states that blacks are overrepresented among the handicapped in America. It addresses the effects of federal cutbacks in social security and their impact on handicapped minorities. It compares some of the negative attitudes toward the handicapped in this country with those in Russia. The article also presents a systematic approach for maintaining federal and state funding for the nonwhite community during this period of fiscal restraint. It calls for intense advocacy by those who work with, support, and represent the minority handicapped in America in an effort to abate the fiscal cutbacks in government.

Based upon prevalence, incidence, and severity, black Americans are clearly in the forefront of disabled persons in America. Causation is varied and complex: birth defects, disease, trauma, war, substance abuse, mental illness, neurological and circulatory conditions.

The arcane program of peremptory disallowance of social security disability benefits without a hearing has created havoc, destruction, and the ultimate ... death, among many disabled persons. As advocates, our role must be to ensure the reinstatement of disabled persons so cruelly, wantonly, and senselessly assailed.

Let's look back to April 1982. In Indiana, Baby Doe was born with Down's Syndrome and digestive tract defects. Her natural parents rejected her. Although there were loving, accepting adoptive parents waiting for her in their warm homes, a judge, acting upon the plea of the natural parents, ruled that it was permissible, legally, to allow Baby Doe to starve to death.

By contrast, in Indiana, a rock group was performing and as part of their act, one of the performers bit off the head of a bat. The performer was arrested for cruelty to animals.

Since the first Baby Doe, there have been several cases with the same outcome. Where was the hue and cry for the rights of the born?

In the absence of such advocacy, the Surgeon-General of the United States, Dr. C. Everett Koop, played a major role in attempting to deal with the problem. He stated, "Each newborn infant, perfect or deformed, is a

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human being with unique preciousness because he or she was created in the image of God." Rules promulgated by the U.S. Department of Health and Human Services (HHS) are designed to protect these infants. The Department is being sued by the American Hospital Association. An appeal on a negative decision by the United States District Court invalidating the HHS rules is in litigation.

Earlier this year, 1984, the Governor of Colorado implied that the elderly were using too many resources and should oblige the rest of society by giving up their lives. You can make your own inferences.

Last year, I was in the USSR to attend a rehabilitation seminar. In Moscow, a city of six million, I was struck by the absence of blind people, the absence of accessibility, the absence of those with birth defects, the absence of a person using a cane or crutch, the absence of the elderly. The same was true in Leningrad, a city of four to five million people. I was not given information about these absences, although I was in the USSR for two weeks. I got the clear impression that the USSR is a society where you produce or you are in trouble. Consider, there is no accessibility: not in buildings, the streets, airports, airplanes, or other public conveyances.

In 1977, the National Urban League and the National Association of Nonwhite Rehabilitation Workers, in cooperation with the White House Conference on Handicapped Individuals, developed a national program designed to examine rehabilitation in nonwhite communities. The program was funded by a federal grant. It is significant that seven years later we must continue to address these concerns.

Within the largest and most successful rehabilitation program in the world, the federal-state program in the United States of America, we see attempts each year to reduce funding and appropriations required to provide rehabilitation services for the disabled. If it were not for the National Rehabilitation Association, its members and friends, program and staff cuts already in progress would have been much more severe. I call your attention to the attached tables showing the administration's fiscal year 1985 budget as compared to the House and Senate recommendations. These figures reflect the efforts on the part of the Congress to appropriate a larger sum of money to the disabled community than that budgeted by the administration (See Appendix).

In order to continue this program, *we must be funded.* That is the bottom line. Your advocacy, your letters and phone calls to your Senators and Congressmen are essential to the continuation of this program. One of the battle cries of the new right is "cut social programs."

Keep in mind that most disabled persons who receive rehabilitation services do become wage earners and taxpayers. For example, in South Carolina, the number one federal-state program in the country and also the number one chapter in the National Rehabilitation Association, there were 8,000 successfully rehabilitated clients in 1982. These 8,000 successes increased their annual rate of earnings from $17.2 million to $55.2 million, a net increase of 66%. Rehabilitation costs are usually a one time expenditure for each client. Among this successful group of 8,000, 50% had mental disabilities. Other disabilities were: digestive tract disorders; hearing impairments; heart and circulatory conditions; allergy and endocrine disorders; visual impairments; epilepsy and other neurological disorders; respiratory diseases; absence of limbs; cancer; speech impairments; blood disorders; and other conditions.

With our active participation to assure continued funding for federal-state programs at minimal levels, we can meet the fiscal demands for rehabilitation needs in the nonwhite community as follows:

- Staff training, to ensure job access to rehabilitation positions at both graduate and undergraduate levels, must be pursued. Effective recruitment methods and programs must be developed within the nonwhite community.
- Outreach programs for disabled persons in nonwhite communities must be established at every point of contact e.g., schools, churches, doctors, hospitals and clinics, unions, worker's compensation, welfare, social security disability, and community organizations. Effective referrals to rehabilitation agencies must be made with adequate follow-up.
- Facilities and facility development must be initiated in nonwhite communities.
- Advocacy for the enforcement of the

Rehabilitation Act of 1973 and its amendments must be more persistent, tenacious, creative, innovative, and effective. Information and information systems as well as stimulation must be provided and utilized to prevent discrimination against disabled persons and to provide public acceptance for these laws. Every available means of communication should be utilized including the media.

- Disabled nonwhite persons must be included at every level in organizations of disabled persons as well as local, state, and federal advisory councils and instrumentalities.
- Immediate steps must be taken to include the nonwhite community in grants programs throughout the rehabilitation community in order to encourage research and innovation.
- Projects with industry must be a *sine qua non* to ensure job opportunities for persons who are disabled in nonwhite communities.
- Accessibility in schools at every level to facilitate mainstreaming must continue.
- Accessibility to vote and voter education are essential for every eligible disabled voter.
- National Rehabilitation Month, September, must be proclaimed as a national priority.

In closing, here is an illustration of "What Went Wrong?" It is a story about four people: Everybody, Somebody, Anybody, and Nobody.

There was an important job to be done and Everybody was sure that Somebody would do it. Somebody got angry because it was Everybody's job. Anybody could have done it, but Nobody did it. Everybody thought that Somebody would do it. But Nobody asked Anybody. It ended up that the job wasn't done, and everybody blamed Everybody when actually Nobody asked Anybody.

In the book of Ecclesiastes, it is said that there is a time for all things. LET US BEGIN!!!

Reference

Duncan, J. (1984). *Washington update*, L-84-15. Alexandria, VA: National Rehabilitation Association.

Appendix

Table I

FISCAL YEAR 1985 APPROPRIATIONS
FOR PROGRAMS AUTHORIZED UNDER THE
REHABILITATION ACT OF 1973, AS AMENDED
($ in millions)

	Administration's Budget	Senate Recommendation	House Recommendation	House & Senate Conference Recommendation
Basic State Grant	$1,003.9	$1,117.5	$1,092.8	$1,100.0
Evaluation (Sec. 14)	.5	2.0	2.0	2.0
Training	5.0	24.0	20.0	22.0
NIHR	30.0	40.0	38.0	39.0
Independent Living (B)	21.0	22.0(B)	21.0(B)	22.0(B)*
(Parts A, C)	--	5.0(A)**	1.0(C)***	5.0(A)**
Service Projects:				
• Client Assistance	-0-	6.3	5.1	6.3
• Special Projects for Severely Disabled****	14.6	13.6	14.6	14.6
• Helen Keller Center (removed from the Act)	3.7	4.2	4.2	4.2
• PWI	11.2	14.4	13.0	14.4
• Indian Tribes	.7	.7	.7	.7
• Special Recreation	-0-	2.1	2.0	2.1
• Technical Assistance	--	.2	--	--
• Migrant Workers****	1.0	.9	.9	.9
National Council on the Handicapped	.3	.7	.5	.7

*Independent Living Centers
**Comprehensive State ILR Services
***Independent living services for older blind
****Special Projects include special demonstration projects, migratory workers, and various other rehabilitation projects for which specific appropriations were not made.
(Duncan, 1984)

Table II

EDUCATION FOR THE HANDICAPPED
($ in millions)

	President's Budget	Senate Recommendation	House Recommendation	House & Senate Conference Recommendation
State Assistance Programs				
State Grant Program	$1,068.8	$1,135.1	$1,125.0	$1,135.1
Preschool Incentives	26.3	28.0	29.3	29.3
Total	$1,095.1	$1,163.1	$1,154.3	$1,164.4
Discretionary Programs				
Deaf-Blind Centers	12.0	15.0	15.0	15.0
Severely Handicapped Projects	4.0	4.3	4.0	4.3
Early Childhood	21.1	22.5	21.1	22.5
Regional, Adult, Voc. & Postsecondary	5.0	5.3	5.0	5.3
Media Services and Captioned Films	14.0	16.5	14.0	16.5
Regional Resource Centers	4.5	6.0	6.5	6.0
Innovation & Development	12.0	16.0	15.0	16.0
Recruitment	1.0	1.0	1.0	1.0
Personnel Development*	37.6	61.0	55.5	61.0
Special Studies	2.0	3.2	3.0	3.1
Secondary Education & Transitional Services	6.0	6.3	6.0	6.3
Total	$119.2	$157.1	$146.1	$157.0

* Includes funds for new Parent Training and Information Program (Duncan, 1984)

Table III

FISCAL YEAR 1985 APPROPRIATIONS FOR SPECIAL INSTITUTIONS
($ in millions)

	President's Budget	Senate Recommendation	House Recommendation	House & Senate Conference Recommendation
Gallaudet College	$46.8	$56.7	$58.7	$58.7
College programs	[38.6]	[37.8]	[39.8]	[39.8]
Model Secondary School for the Deaf	[4.9]	[12.2]	[12.2]	[12.2]
Elementary School	[3.2]	[6.6]	[6.6]	[6.6]
National Technical Institute for the Deaf	31.4*	31.4	31.4	31.4
Total	$124.9	$144.7	$148.7	$148.7
P.L. 89-313 State Operated Schools	$146.5	$153.8	$146.5	$150.1

*Of this amount, $1.4 million is requested for construction.

(Bracketed figures refer to amounts previously appropriated or proposed.)

Table IV

FISCAL YEAR 1985 APPROPRIATIONS FOR DEVELOPMENTAL DISABILITIES PROGRAM
($ in millions)

	President's Budget	Senate Recommendation	House Recommendation	House & Senate Conference Recommendation
State Grants	$45.4	$50.2	-0-	$50.2
Protection & Advocacy	8.4	13.7	-0-	13.7
Special Projects	2.6	2.7	-0-	2.7
University Affiliated Facilities	7.8	9.0	-0-	9.0
Total	$64.2	$75.6	-0-	$75.6

(Duncan, 1984)

2 • Redefining the Unacceptable

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Abstract

This article presents a general overview of the emerging role of rehabilitation and related services and how they have evolved to reflect conventional approaches. Legislation likewise has been enacted to address fragmented services and unacceptable barriers to rehabilitation. The formation of the National Institute of Handicapped Research (NIHR), which was the result of the Rehabilitation Act of 1973, and its funding options designed to support grants to improve services to special populations, are highlighted. Finally, reference is made to the Presidential Order 12320 which addresses priority for the funding of such grants.

The history of rehabilitation is a continuing redefinition of the unacceptable. Early in this century, the waste of human productivity caused by accidents in mining, railroad building, lumbering, and other heavy and dangerous industries became unacceptable. The rehabilitation solution was simply vocational retraining. Later, during and after World War I, added emphasis was given to physical restoration and improved artificial limbs. However, virtually all those with paraplegia died within a few weeks or months.

Epidemics and high-prevalence diseases such as polio and tuberculosis likewise presented unacceptable outcomes for those with disabling effects. Such conditions were a major stimulus in the development of the field of physical medicine and rehabilitation. In fact, the two physicians who wrote the first medical specialty examinations in this field had close involvement with these illnesses. Dr. Frank Krusen of the Mayo Clinic had recovered from tuberculosis and Dr. Miland Knapp, an orthopaedic surgeon, was concerned with the poor functional outcomes of persons whose limbs and joints were immobilized by splints and braces following disabling attacks of polio.

Then came World War II. Conventional wisdom said that sick people belong in bed and prolonged bed rest following surgery and obstetrical delivery were essential to recovery. A young medical officer, Dr. Howard Rusk, found the conventional medical wisdom to be unacceptable. Within limits of physical tolerance, patients on his wards, especially those with acute pneumonia, were kept physically active. The body was made for use. Forced inactivity, except when absolutely essential, is unhealthy. Rusk developed an approach he called "rehabilitative medicine." After World War II, the two approaches merged and became "Physical Medicine and Rehabilitation."

About this time, perhaps the most influential woman in government service, Mary Switzer, came on the scene. She found the fragmented and partial approaches to be unacceptable. She found the generally low level of professional training to be unacceptable. She found the tendency to stereotype the handicapped to be unacceptable. Many of the rehabilitation programs in the U.S. and abroad are a tribute to her farsighted leadership.

Since 1968, more than ten federal acts or amendments recognized that the de facto limitations on the civil rights of disabled persons were likewise unacceptable (DeJong and Lifchez, 1983). These include the Architectural Barriers Act of 1968 (P. L. 90-480); Accessible Mass Transit Act of 1970 (P. L. 91-453); Accessible Highway Facilities, 1973 (P. L. 93-87); the Section 504 Anti-discrimination Provisions of the 1973 Rehabilitation Act (P. L. 93-112); Protection and Advocacy

Systems for Developmentally Disabled Persons Act of 1975 (P. L. 94-103); The Education for All Handicapped Children Act of 1975 (P. L. 94-142); The Independent Living Priority of the Rehabilitation Amendments of 1978 (P. L. 95-602); and the removal of some work disincentives under the Social Security Amendments of 1980 (P. L. 96-265).

In 1978, Congress passed another piece of far-ranging legislation regarding the unacceptable state of knowledge in rehabilitation. This was Title II of the Rehabilitation Act of 1978 which established as a separate federal agency the National Institute of Handicapped Research (NIHR).

This morning, I will describe briefly the important authorities under this act, its current activities as they pertain to this conference; pertinent priorities, represented in its soon to be released long-range plan; and some observations on how the results of meetings such as this can influence priorities for rehabilitation research.

NIHR was established to emphasize the application of the methods of materials of science and technology to the challenges of disability and loss of normal function. It removed age barriers from such research. It was to include all ages, from birth to old age. It encompassed the full range of participants—disabled persons, parents and advocates, educators, physicians, therapists, behavioral scientists, engineers, and technologists, among others.

We were to develop a five-year plan every three years as a guide to all disability research, not just that supported by NIHR. The Director was to convene on a quarterly basis an Interagency Committee on Handicapped Research through which representatives of some twenty-nine federal agencies with identifiable interest in this field could coordinate their efforts and avoid unnecessary duplication of effort. We were to develop a national plan to communicate the results of research and technological development to all appropriate audiences throughout the country. We were to experiment with the use of telecommunications technology in closing communications gaps in rehabilitation information. Finally, we were required to keep in touch with other rehabilitation research programs throughout the world. Since 1978, impressive accomplishments have been achieved in each of these areas. I would invite specific inquiry regarding any of them, but I will move on quickly to current work in NIHR pertinent to your interests.

CURRENT WORK PERTINENT TO THIS CONFERENCE

This meeting is part of an NIHR-funded grant directed at the important priority of improving delivery of rehabilitation services to special populations. This initiative was in response to the Presidential Order 12320. This grant was the result, in part, of an invitational conference organized by our staff person, Ms. Rheable Edwards, to inform historically black colleges and universities of opportunities in rehabilitation research.

NIHR supports other grants to improve services to special populations. About 18 months ago, we convened a state-of-the-art conference on rehabilitation research needs regarding the Hispanic population in the United States. The first grant resulting from this effort was initiated last summer with Pan American University in Texas. We also support a research and training center (RTC) in geriatrics rehabilitation at Rancho Los Amigos in California which includes an emphasis on older disabled Hispanic persons who often do not use available rehabilitative services because of cultural barriers.

Two small RTC's addressing the needs of native Americans are supported through Northern Arizona State University and the University of Arizona. This work has led to an interest by the Indian Health Service to include rehabilitation assessment as part of their hospital program.

The University of Hawaii has also entered into an agreement with NIHR to study the rehabilitation needs of the native residents of the U.S. trust territories of Micronesia.

New NIHR funding options include the individual research fellowship program which seeks to expand the pool of leadership in rehabilitation research; the Innovative Grants Program to stimulate new ideas and opportunities in rehabilitation research and service programs; and the Field Initiated Research Grant Program which provides up to three years of support for well-designed research projects.

In keeping with the Presidential Order 12320 and the authority of the Director for final selection of projects from those eligible

for support, it is the intention of the Director to give priority to applications from historically black colleges and universities. Those interested may want to contact Ms. Edwards of our staff. Although these programs are published without specific priorities, NIHR has particular interest in early intervention in families with disabled children; early intervention in work-related disability; transition of disabled persons from school to work; economics of disability and rehabilitation; technology and disability; and independent living.

If the history of advances in rehabilitation of disabled persons is a continuing "Redefinition of the Unacceptable," let us plan now to take bold new steps in removing the unnecessary and unacceptable barriers to full participation in community life of disabled persons. Your project here at Howard is pointing the way.

Reference

DeJong, G., & Lifchez, R. (1983). Physical disability and public policy, *Scientific American, 42.*